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ABSTRACT

A pilot study was designed to provide 11 parents of special education children with the opportunity to share common concerns about their children and to share the feelings that can often be roadblocks to their child's progress. Participants as well as 61 parents of newly identified handicapped children and 51 professionals filled out the Parental Needs Questionnaire. Results showed that professionals' focus on the feelings of parents of handicapped children is often inaccurate. The 10 items wherein the perceived needs were significantly different from the expressed needs involved the feelings of guilt, anger, and fear. The remaining 10 items on which parents and professionals had general agreement reflect feelings of anger, fear, helplessness, and hurt. A ranking of questionnaire items is included. (SB)

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THE PERCEIVED VERSUS THE EXPRESSED NEEDS OF PARENTS OF HANDICAPPED CHILDREN

Joan M. Gibson, Ph.D. and Dorothy Young-Brockopp, Ph.D.

Families of special children need a great deal of information and help to provide a successful learning environment in the home and to participate effectively in their child's educational planning. These parents often have a deeper and more primary need to develop acceptance toward their child and the child's handicap. Because of the increased rights and responsibilities of parents of special children and their participation in educational planning, their acceptance of the child assumes great importance.

"Appropriate services" for a handicapped child, beyond the direct educational programming provided by Public Law 94-142, the Education for All Handicapped Children Act, incorporate parent counseling and training, as well as child development information for parents. Professionals such as Barsch[2], Ginott[7], and Rappaport[10] have long emphasized the utilization of parents in remedial programs for special children.

Effective programming for parents requires the staff to have knowledge of the fears, concerns, and needs of the parents, and also to have the necessary skills in consulting, counseling, and teaching parents methods to facilitate their child's academic and social development. Programs of parent counseling, in general, seem to focus

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on providing parents with emotional support, knowledge, and skill development related to their handicapped child.

Parent counseling and training programs seem to deal with the feelings of the parents, although some programs more directly than others. In some programs, the obvious purpose is to provide the parents with information concerning the handicap itself, and to help define the implications of the handicap specifically for each family. When dealing with this information, parents inevitably begin to express their reactions and feelings about their child's condition and behavior. The primary importance given to information in such programs is often based on the belief that much anxiety grows from a lack of knowledge.

Those parent programs which are more direct in dealing with feelings consider it imperative to help parents work through their own feelings about being the parents of a handicapped child. Information alone at this time cannot be the answer. Information is certainly held to be a vital necessity to clear up many misconceptions and confusion, but in itself, can only be a beginning.

Both of these approaches are often effectively combined in a psychoeducational format.[1,3] The combined format reflects the findings that parents want both information and the opportunity to look at and express their feelings.[4]

Whether the "feelings" come before or after the "information," general agreement is found in the literature concerning the perceived emotional needs of these parents.[5,11,13] Many authors conceptualize parents' feelings in terms of stages. Smith[12] writes about the stages

of denial, flight, isolation, guilt, anger, blame, fear, envy, bargaining, depression, mourning, and acceptance and hope. Huber[8] uses Kubler-Ross' model of loss as a framework to understand parents' feelings and encourages professionals to deal with parents appropriately as being in the stage of denial, anger, bargaining, depression, or acceptance. Stages, although developmental, may be reexperienced and worked through again and again.

Many studies indicate that parent counseling may be more beneficial in many situations than direct therapy or remediation with the child.[5] More specifically, even outstanding educational and therapeutic programs will probably little benefit the handicapped child without support and assistance from the parents.

Is the information received by the parents from the professionals adequate and appropriate as far as the parents are concerned? Dembinski and Mauser[6] find this is not the case.

Is the focus on feelings accurate? Feelings and perceptions are often not predictable or logical and therefore are not simple to deal with. A pilot study was therefore devised to compare the perceived versus the expressed needs and feelings of parents of handicapped children. The goals and purpose of a parent program logically stem from the perceived needs of the parents. If a discrepancy exists between the perceived needs and the expressed needs, then program development may be mistakenly based and hence ineffective.

PROCEDURE

The pilot study was designed to provide parents of special children with the opportunity to share common concerns about their children and to share the feelings that can often be roadblocks to their child's progress. The assumption is that such sharing helps people get in touch with their own feelings and learn that others may have similar feelings and experiences -- a discovery which in itself helps acceptance. As members gain comfort and experience in sharing their feelings, they may begin to evaluate their own feelings and identify areas where they have misunderstandings or lack of knowledge.

Selection criteria were established so that members would consist of parents of newly identified handicapped children. The most crucial and also most traumatic interval in the lives of parents of a handicapped child appears to be between the moment they learn of their child's handicap and the time they realize what alternatives are available to them. This interval is often characterized by strong emotional upheaval as the parents attempt to clarify and integrate within themselves the meaning of their child's condition.[9] Assistance at this time can enable parents to learn less painful ways of dealing with the mental, physical, and emotional adjustments required to parent a disabled child.[4]

The parent support group was devised and implemented with the cooperation of the Parent Education Program and the Pupil Personnel Department of the Buffalo Public School System. One of the six System subcommittees on the handicapped was selected as the pilot study center. The records of over eighty families were screened. Thirty families

were finally contacted and invited to participate. Eleven volunteers formed the group -- three couples and five single parents. The group met for one and one-half hours, one evening each week for seven weeks. The weekly attendance varied between seven and ten members.

From these sessions several areas of parental concerns were identified. This information along with information taken from the literature provided the basis for the development of an instrument designed to assess and rank parents' needs. Each parent in the group responded to the instrument by weighting 25 items on a 9-point Likert-type scale. Using the responses to the initial instrument, a questionnaire (The Parental Needs Questionnaire - Appendix A) was developed that reflected the major concerns of the parents. The final instrument contained 20 items on a 7-point Likert-type scale.

At the same time that the parents in the group responded to the initial instrument, several professionals within the school system who have some contact with these parents also responded to the items. Comparisons of the expressed with the perceived feelings point out several areas of misperceptions on the part of the professionals.

In order to gain a more representative sample of parents, Parental Needs Questionnaires were sent to sixty-one parents of newly identified handicapped children. The handicapping conditions include learning disabilities, learning adjustment, and educable mentally retarded. Fifty-one professionals were surveyed with the same questionnaire. The professionals are staff members of the sub-committees on the handicapped. The staff members include school psychologists, social workers, counselors, diagnosticians, speech

therapists, and coordinators of the subcommittees. Each staff member has a varying degree of contact with the parents of the children being referred through the subcommittees.

RESULTS

Univariate and multivariate analyses of variance were used to (1) rank the responses of the parent group, and (2) discover any significant differences between the responses of parents and professionals. The multivariate analysis of the responses for all twenty items by the twenty-two parents and the twenty-three professionals in the sample yields an F statistic of 4.6785 (d.f. 20, 24) and a p value of .0003. The overall response of the parents differs significantly from the overall response of the professionals.

Table 1 shows the ranking of the mean weights of parents' responses to the twenty items, beginning with those items with which the parents are in most agreement.

Insert Table 1 about here

Table 2 shows those specific items for which responses are significantly different for parents than for professionals.

Insert Table 2 about here

Five items (#12, 13, 14, 16, 19) have mean weights that reflect parental agreement in regard to that statement. Fifteen items have mean weights that reflect mild parental disagreement to strong disagree-

ment. Ten items (#1, 3, 5, 6, 7, 8, 10, 15, 17, 20) are significantly different for professionals than for parents. The significance levels range from .0001 to .03. The direction for the difference is the same in all cases. For each item professionals tend to agree with the item while parents tend to disagree.

DISCUSSION

According to the results of this study, the professionals' focus on the feelings of parents of handicapped children is often inaccurate. While these inaccuracies may be due to parental denial or differences in the stage of acceptance of their child's handicap, they may also be due to the projections and/or assumptions of professionals. If the inaccuracies are due to such projections and/or assumptions, interventions by the professionals will be less effective.

The inaccuracies found in this study can be viewed from at least two perspectives. First, the ten items wherein the perceived needs are significantly different from the expressed needs involve the feelings of guilt, anger, and fear. The remaining ten items on which parents and professionals have general agreement reflect feelings of anger, fear, helplessness, and hurt. A possible interpretation is that professionals are accurate most of the time when perceiving parents' hurt and helplessness, are accurate some of the time when perceiving parents' fear and anger, and seem to be somewhat oversensitive to parents' guilt. Professionals, therefore, may presume the existence of more fear, anger, and guilt than the parents experience or are ready to acknowledge.

Second, for each item wherein the perceived and expressed needs differ significantly, the direction of the responses is consistent. The direction of the professionals' response is always toward the agreement end of the scale while the direction of the parents' response is toward disagreement. Professionals apparently assume the existence of many feelings and needs that parents do not acknowledge.

The results viewed from either perspective suggest that when dealing with the parents of handicapped children some professionals may be working with false assumptions or stereotypes. Professionals may be projecting certain needs and feelings on the parents rather than assessing individual needs. Bricklin[3] points out that many members of the helping profession have mixed feelings towards these parents, stemming at times from their own self-anger at parents, or from their own ambivalent feelings towards their own parents, or at times from their belief that parents are in fact responsible for some of their children's problems. When professionals assume rather than assess the existence of parents' needs, their ability to intervene appropriately is lessened. A professional's effectiveness, in part, rests on addressing what is important to the parent. Parents who feel misunderstood are less able to build a trusting relationship with the professional, a relationship which would enable the parents to deal with thoughts and feelings they find unacceptable or damaging. Only when the professional is willing to work with the parent at the parent's own pace, as suggested by Huber[8], will parents be provided with the necessary emotional support to allow their feelings to emerge and thus proceed to personal growth.

Table 1

RANKING OF MEAN WEIGHTS AND STANDARD DEVIATIONS OF PARENTS' RESPONSES TO TWENTY ITEMS

ITEMS	MEAN	SD
19. When my child hurts because of his/her problems, I hurt.	5.73	1.63
12. I feel annoyed that my child wasn't diagnosed sooner.	4.81	1.99
13. I feel helpless when people expect my child to be just like others and he/she isn't.	4.59	1.92
14. I ache for my child when his/her friends don't understand his/her problem.	4.59	1.99
16. I've been afraid for a long time that something was wrong with my child.	4.32	2.23
2. I'm angry that there aren't more professional services for my child.	3.95	1.78
18. I feel helpless when school officials won't listen to me.	3.77	1.90
4. I feel hurt that few people at school really care about my child.	3.68	1.91
8. I often feel helpless to do anything to help my child learn.	3.36	1.7.
5. I feel guilty because I haven't been able to do enough for my child.	3.32	1.35

Table 1 (con't)

ITEMS (con't)	MEAN	SD
3. I often feel that I am alone in trying to help my child.	3.27	1.61
11. I'm afraid that my child was diagnosed too late to do much for him/her.	3.10	1.97
9. I feel hurt that my family and friends don't seem to understand my feelings.	3.04	1.64
6. I'm afraid that my child will not be able to support him/herself.	3.00	1.69
7. I feel angry that my child has a problem.	2.95	1.53
10. Somehow I think my child's problem is my fault.	2.90	1.37
1. I'm afraid that my child will not have a normal life.	2.86	0.83
20. I feel guilty because I spend more time with this child than with my spouse or other children.	2.68	1.52
17. I feel annoyed sometimes that this child takes so much of my energy.	2.36	1.55
15. I feel guilty sometimes for wishing this child wasn't here.	1.77	1.31

Table 2

SIGNIFICANT DIFFERENCES IN WEIGHTED RESPONSES BETWEEN PARENTS AND PROFESSIONALS

ITEMS	MEANS PARENTS	MEANS PROF.	p
1. I'm afraid that my child will not have a normal life.	2.86	4.52	.0001
3. Ioften feel that I'm alone in trying to help my child.	3.27	4.56	.0022
5. I feel guilty because I haven't been able to do enough for my child.	3.32	4.17	.0367
6. I'm afraid that my child will not be able to support him/herself.	3.00	4.57	.0021
7. I feel angry that my child has a problem.	2.95	4.39	.0033
8. I often feel helpless to do anything to help my child learn.	3.36	5.04	.0008
10. Somehow I think my child's problem is my fault.	2.90	4.43	.0006
15. I feel guilty sometimes for wishing this child weren't here.	1.77	3.26	.0013
17. I feel annoyed somtimes that this child takes so much of my energy.	2.36	4.22	.0001
20. I feel guilty because I spend more time with this child than with my spouse or other children.	2.68	4.17	.0007

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APPENDIX A

Parental Needs Questionnaire

1. child's placement ___LD resource room
___LD self contained
___Learning Adjustment
___Mentally retarded

2. child's age _____

3. your age _____

4. your sex: M F (circle)

5. Do you have any other children in special education classes?
yes___ no___

For each item below, please indicate the response closest to your opinion by circling the appropriate number. Please respond to each statement and circle only one number.

	very strongly disagree	strongly disagree	disagree	agree	strongly agree	very strongly agree	most strongly agree
1. I'm afraid that my child will not have a normal life.	1	2	3	4	5	6	7
2. I'm angry that there aren't more professional services for my child.	1	2	3	4	5	6	7
3. I often feel that I am all alone in trying to help my child.	1	2	3	4	5	6	7
4. I feel hurt that few people at school really care about my child.	1	2	3	4	5	6	7
5. I feel guilty because I haven't been able to do enough for my child.	1	2	3	4	5	6	7
6. I'm afraid that my child will not be able to support him/herself.	1	2	3	4	5	6	7
7. I feel angry that my child has a problem.	1	2	3	4	5	6	7
8. I often feel helpless to do anything to help my child learn.	1	2	3	4	5	6	7
9. I feel hurt that my family and friends don't seem to understand my feelings.	1	2	3	4	5	6	7
10. Somehow I think my child's problem is my fault.	1	2	3	4	5	6	7
11. I'm afraid that my child was diagnosed too late to do much for him/her.	1	2	3	4	5	6	7

	very strongly disagree	strongly disagree	disagree	agree	strongly agree	very strongly agree	most strongly agree
12. I feel annoyed that my child wasn't diagnosed sooner.	1	2	3	4	5	6	7
13. I feel helpless when people expect my child to be just like others and he/she isn't.	1	2	3	4	5	6	7
14. I ache for my child when his/her friends don't understand his/her problem.	1	2	3	4	5	6	7
15. I feel guilty sometimes for wishing this child weren't here.	1	2	3	4	5	6	7
16. I've been afraid for a long time that something was wrong with my child.	1	2	3	4	5	6	7
17. I feel annoyed sometimes that this child takes so much of my time and energy.	1	2	3	4	5	6	7
18. I feel helpless when school officials won't listen to me.	1	2	3	4	5	6	7
19. When my child hurts because of his/her problem, I hurt.	1	2	3	4	5	6	7
20. I feel guilty because I spend more time with this child than with my spouse or other children.	1	2	3	4	5	6	7